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ABSTRACT

This paper proposes that those who make policy for individuals with severe disabilities ought to evaluate current actions and frame proposed changes according to whether these changes protect or increase citizens' opportunities to build inclusive community by establishing suitable position and priority for adequate government investment. Such policies would reposition state and federal government towards the role of guarantor of civil rights, ensurer of adequate cash income for people with disabilities and their families, and underwriter of a variety of means to assist these individuals to manage their situation or find their place in community life. Development of such policies to establish priorities in government funding requires consideration of such questions as: How can we decrease disincentives to participation in community life?; How can we ensure sufficient cash income for people with disabilities?; How can we increase options for direct control of the specific supports people require?; and How can we invest in activities that build inclusive community? Decision makers who increase foresight, make explicit the image of people with disabilities underlying their policies, and state the links between their decisions and the growth of inclusive community will make better policies than decision makers who neglect to explore these three perspectives. Successful exploration depends on involving people with different positions, including the people with disabilities who are intended to benefit, their allies, and the people who will actually provide assistance and offer opportunities. (JDD)

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DESIGNING POLICIES IN SUPPORT OF INCLUSIVE COMMUNITY: QUESTIONS FOR DECISION MAKERS

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John O'Brien

Designing Policies in Support of Inclusive Community

Questions for Decision Makers*

People in association create neighborhoods, schools, workplaces, marketplaces, and civic organizations. They build inclusive community when their activity calls on, strengthens, and celebrates mutual capacity to welcome, join with, and care for people who have been left out. They diminish community when their activity excludes and isolates people and substitutes bureaucratic control for mutual concern and initiative.

Federal and state government and their agents play a large and growing part in the lives of people vulnerable to exclusion because of severe disability. Policies shaping federal and state action should protect or increase citizens' opportunities to build inclusive community by establishing suitable position and priority for adequate government investment. Whether they are legislative, judicial, or executive decision makers, or agency administrators, or citizens advocating for policy change, those who make policy ought to evaluate current actions and frame proposed changes according to these two complementary sets of questions.

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* These notes are one result of a discussion sponsored by Northspring Consultants with the assistance of the Connecticut Developmental Disabilities Council on 28 September 1989. Many participants in the discussion were informed by a paper prepared by John McKnight, *Do no harm: A policymaker's guide to evaluating human services and their alternatives*. While these notes arise from the discussion, they represent my own efforts to clarify a position and stimulate further argument. It is not an adequate summary of the richly varied and sometimes conflicting perspectives of other participants.

Preparation of this paper was partially supported through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

I. Questions that establish priority of government funding

Following this sequence of design questions over time will reposition state and federal government in the lives of people with severe disabilities. Instead of being a funder, regulator, and provider of bureaucratically organized, professionally controlled disability services, government becomes guarantor of civil rights, insurer of adequate cash income for people with disabilities and their families, and underwriter of a variety of means to assist those people with disabilities who need help to manage their situation or find their place in community life.

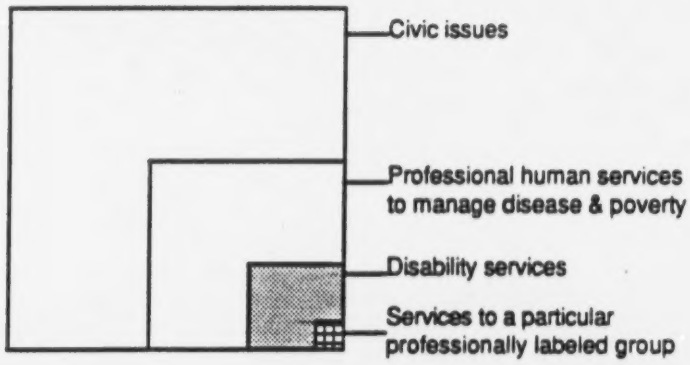
For all government decision makers:

➢ How can we decrease disincentives to participation in community life?

Insufficient and inaccessible transportation, inaccessible buildings, discriminatory hiring or enrollment practices, insufficient affordable housing, denial of insurance, and perverse incentives in income support programs bar people with disabilities from many public places and much productive activity. In dealing with these civic issues, government policy makers and their agents often view people with disabilities as a special interest distracting from their primary concern. Skillful assertion of the civil rights of people with disabilities responds to barriers to access to existing resources, though not to obstacles imposed by insufficient supply.

Political involvement of citizens with disabilities and their allies in the definition and resolution of civic issues improves the chances that supply of opportunities and public resources will become more adequate for everyone.

The way services for people with disabilities have grown makes it difficult to shift energy toward decreasing barriers to community participation through better overall response to common needs for housing, employment, transportation, health care, and adequate income support. Concerned government decision makers and many advocates have cooperated to focus attention on increasing funds and legal regulations for services divided by professional categories (the set of little boxes in the lower right corner of this diagram).


Civic issues
Professional human services to manage disease & poverty
Disability services
Services to a particular professionally labeled group

Within this context, most advocates for people with disabilities have worked around unresolved civic issues by setting up "special" alternatives for people with disabilities.

Transit for eligible people with disabilities supplements insufficient, inaccessible public transit; congregate housing operated by service agencies makes up for defects in local housing supply; a sheltered occupation center offers places to people excluded from ordinary work places; special schools take students rejected by regular schools. For most of the people who rely on these arrangements, fixed attention on increasing or maintaining or rearranging financial allocations within the "disability services" box seems like a matter of survival. And increasing the power of federal and state government to regulate its provider agents seems like the surest way to better lives for people with disabilities.

The space in which civic issues are decided is not a well ordered forum waiting to welcome people with disabilities into influential roles as soon as greedy professionals release them from services. Like citizens concerned about people with disabilities, citizens concerned about public transit, housing, healthcare, welfare reform, and economic development also work against fragmentation of issues, boundary confusions, domination by experts and insiders, disagreement about goals and methods, and disorganization of groups seeking change.

Active involvement in reducing disincentives to community participation may be messy, but it is necessary. Politically concerned people with disabilities and their allies will have more energy to address civic issues when federal and state policy makers give priority to answering the next three questions.

For decision makers responsible for human services:

➢ How can we insure sufficient cash income for people with disabilities?

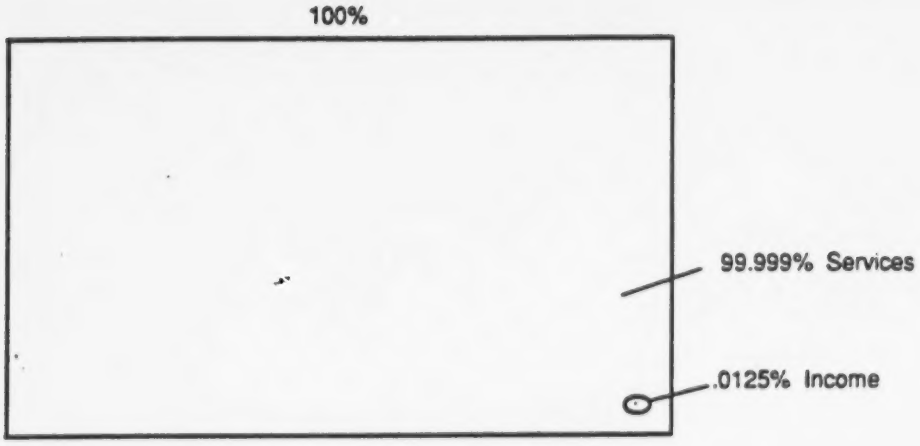
Sufficient income means that a person has...

...enough money to support a **reasonable standard of living**: a decent home, good general health care, and the means to take part in community life

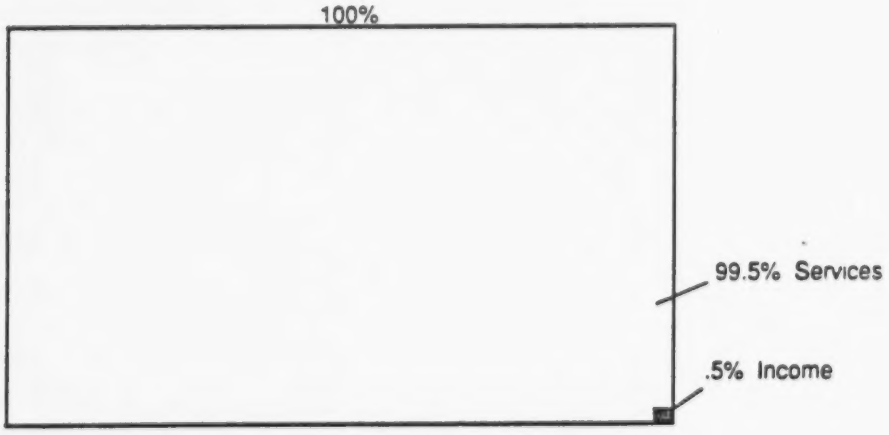
plus

...the money to purchase **necessary supports** required because of the person's disability: personal assistants, equipment and supplies, physical adaptations, the choice of help to learn skills, desired professional services (such as help with communication or mobility), and desired assistance to locate and coordinate supports

A policy of assuring sufficient income would reverse present policy for people with mental retardation, symbolized by these two comparisons of allocation to income versus services. The first identifies the proportion of a state's mental retardation services budget intended to increase income (the approximate proportion is represented by the small dot inside the circle). The second shows the proportion of all benefits available to a nominal recipient who receives 24 hour services in a state operated ICF-MR (intermediate care facility for the mentally retarded).



Approximate proportion of FY 1989 Connecticut Department of Mental Retardation budget allocated to service provision versus increasing cash income of program participants



Approximate proportion of state and federal funds allocated to services versus income for a person resident in a New Hampshire state institution in FY1987

For most adults with disabilities, assuring sufficient income means supplementing people's earnings through **direct cash grants**. For children with disabilities it means supplementing family income through direct cash grants. Experimentation with voucher systems or intermediary agencies which administer agency funding as if it were a cash grant to people with disabilities may be more immediately feasible than direct money payments, but they compromise the desired position of federal and state government as redistributor of income rather than funder of service.

This priority raises many challenging problems beyond the question of how to create the political will to overcome entrenched interests in a directly funded service system which most citizens understand and justify as a professional-bureaucratic response to disease and poverty. As the proportion of funds re-allocated from services to income rises, a variety of thoughtful answers to questions like these become urgent:

- How to liquidate existing services, assuming that the policy of increasing income means more than passing money through a client back to a service providing agency?
- How to determine eligibility, establish appropriate levels of cash support, and manage accountability for the funds people receive, assuming that the goal is to insure adequate income in disposable form for each person rather than simply to divide existing allocations evenly among current recipients? Review of the history of benefits programs, like SSI and SS-DI, and programs that purchase services on an individual's behalf, like vocational rehabilitation, will refine these questions.
- How, if at all, to regulate the market in personal assistance and specialist support?
- How to insure a sufficient level of public investment for all people with disabilities?

How far will the money go? A preliminary exercise in testing assumptions

Simple arithmetic demonstrates that equal division of a state's total public expenditures on mental retardation services among current program recipients would result in a substantial increase in their income. A well resourced state might serve about 10,000 people with a budget of about $300,000,000 yielding a potential individual income of $30,000 minus the per person cost of administering the individual cash grants system.

However, even this unusually high level of spending on a particular disability group leaves significant numbers of this group without support for housing and others waiting for more than token assistance. The denominator in the division of the total budget will also grow when arbitrary diagnostic barriers to support are removed. For instance, many people with developmental disabilities now ineligible for mental retardation services are confined in nursing homes or constricted in their own or family homes by lack of adequate supports. These people probably don't extend the total dollars available for redistribution in the same proportion as people now serviced at higher cost.

Furthermore, though everyone has a favorite story of bureaucratic waste or costly overservice, it isn't obvious that enough money is now wasted to offer all people with severe disabilities an adequate income. Just wages for personal assistants, fees for desired specialized assistance now packaged with services, and sufficient allowance for rents and transportation can't be compromised to make proposals look more attractive. Neither can costs be reduced by optimistic assumptions about supports that family or friends will offer for free.

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➢ How can we increase options for direct control of the specific supports people require?

Increasing cash income doesn't necessarily increase people's direct control of the supports they rely on. People with no option but to turn their money over to a licensed residential or attendant care provider may be a bit better off as "private pay" patients, especially if there is real competition among licensed agencies, but they remain patients. To increase people's autonomy...

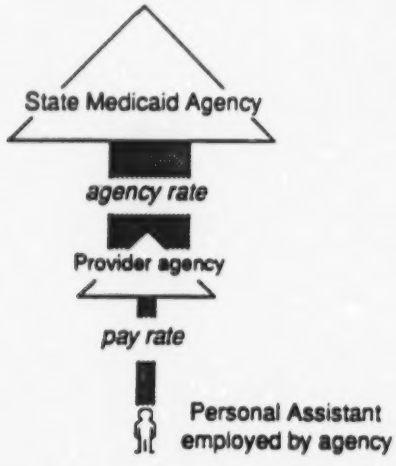
- Demedicalize and deprofessionalize services. For example, professional licensing, such as nurse practice acts, often pose unnecessary barriers to a person with a disability hiring, training, and supervising personal assistants of their own choice.

- Remove incentives for the creation of bureaucratic intermediaries, especially incentives to create larger intermediary agencies.

- Encourage a variety of ways to manage living and support arrangements for people unable to manage for themselves. Guardianship laws and arrangements need careful review. Alternatives to legal guardianship, such as informal management of supports by family members or unpaid friends, need development.

- Encourage a variety of ways to empower people with disabilities and their families. Circles of support, peer counseling among people with disabilities, family support groups for the parents of children with disabilities, and groups that bring people together across existing disability group lines are important starting points. Good information makes a difference and the greater the variety of successful arrangements, the greater the potential information for information overload. Stories of people's lives are the best means to communicate much of the information that people need.

- Make present overhead costs available to people with disabilities so they can invest in a variety of coordination and development activities. In many places, the present situation looks like this:



Two intermediary agencies charge to control the dispersal of funds, set the conditions for provision of assistance, recruit, hire, train, and supervise assistants.

When overhead costs beyond the minimum necessary to disburse cash grants go directly to people with disabilities, several alternatives become possible:

- ✓ A person with a disability can coordinate, hire, train, and supervise assistance for him or her self and keep the money.
- ✓ A person with a disability can hire someone to assist with some or all of coordination and management tasks.
- ✓ A group of people with disabilities can form a cooperative to perform tasks they believe can be done more effectively collectively* (such as developing a pool of personal assistants or an equipment repair service).

➢ How can we invest in activities that build inclusive community?

Some activities that bring previously excluded people into community deserve public support, at least during the time of transition from government funding of services to government cash grants to individuals. Such activities would assist people with disabilities and their families...

- To clarify their preferences for assistance and to invent options for honoring a variety of preferences
- To develop personal support by assisting people to form new relationships and draw together circles of support
- To determine the best individual balance between paid assistance and unpaid care
- To organize ways to deal with the possibility that vulnerable people could be neglected, abused, or exploited

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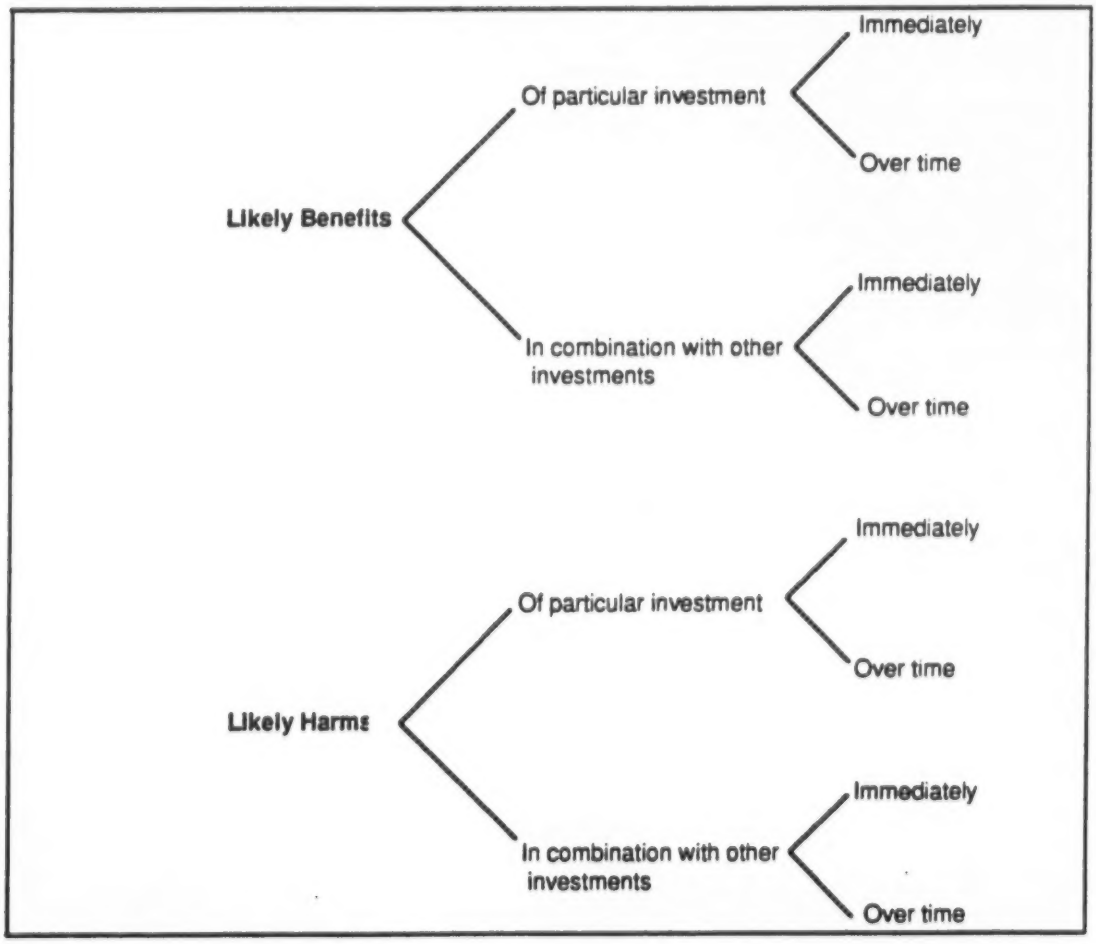
* See Adolf Ratzka (1986). *Independent living & attendant care in Sweden: A consumer perspective*. New York: World Rehabilitation Fund.

II. Questions to evaluate the impact of service policy decisions

Decision makers who increase foresight, make explicit the image of people with disabilities underlying their policies, and state the links between their decisions and the growth of inclusive community will make better policies than decision makers who neglect to explore these three perspectives. Successful exploration depends on involving people with different positions, including the people with disabilities who are intended to benefit, their allies, and the people who will actually provide assistance and offer opportunities.

It is as important to examine existing policies and investments as to scrutinize proposals.



Increase foresight

Human service policies are less likely to be counterproductive when decision makers develop explicit responses to three questions:

- Over time, what do we believe will be the **benefits** of this policy?
- Over time, what do we believe will be the **harms** from this policy?
- How could initial benefits deteriorate over time?

Each question needs to be examined both for the proposed policy and for its cumulative effects with the aggregate of other existing policies.* In considering each of these questions, it's important to guard against exaggerating benefits and minimizing harms.

Make the image of people with disabilities explicit

Every policy makes a statement about, and strengthens, the social role of people with disabilities. Making this image explicit allows a check on the consistency of the policy with insuring people with disabilities a range of positive roles. Many existing policies interpret people with disabilities as sick, pitiful, incompetent to choose, or otherwise as passive recipients of professional services.

State the links between the policy & strengthening inclusive community

Each policy arises from, and reinforces, qualities in community life that either build inclusiveness and mutual care or contribute to isolation and individualism. This diagram suggests some of the polarities in community life. Decision makers can identify how they intend a policy to express and influence each.

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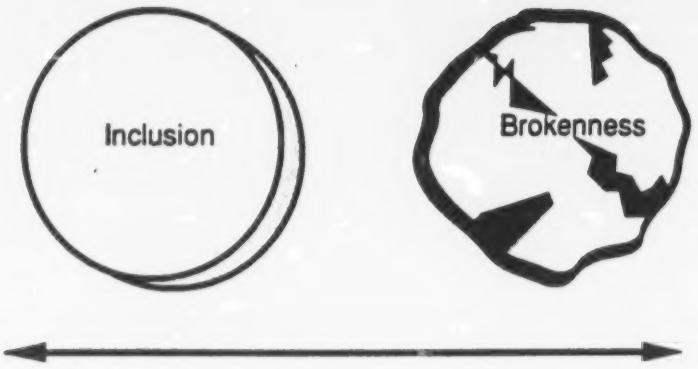
* For an extended discussion of this issue, see J. McKnight (1989). *First, do no harm.* pp 10-13. Also see D. Kallenback & A. Lyons (1989). *Government spending for the poor in Cook County, Illinois: Can we do better?* Evanston: Center for Urban Affairs & Policy Research, pp. 22-27.



• Hospitality	#Fear & hostility to apparent strangers
• Sharing	# Exclusiveness & search for threatening distinctions
• Care & respect for autonomy	#Professional control
• Free association to pursue shared interests	# Individualism
• Culture as basis of positive identity within diversity	# Culture as defense for withdrawal
• Search for capacity	# Fear of scarcity
• Problem solving for development	# Problem solving to protect privilege.